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# Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective

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## ABSTRACT

**Background:** Individuals with intellectual and developmental disabilities (IDD) represent a particularly vulnerable group to the threats posed by COVID-19. However, they have not yet been given a voice on how their living conditions have been affected by COVID-19.

**Aims:** This study aims to report the impact on people with IDD of COVID-19 and the response measures applied in Spain during the lockdown.

**Method:** Data on 582 individuals with IDD were collected through a survey. Seven open questions were included to capture the perspectives of people with IDD on COVID-19 and its consequences. Content analysis was performed to identify themes and categories across participant responses. Chi-square tests were used to analyze the relationship between reporting a specific category and participants' characteristics.

**Results:** Supports have been conditioned by the living context. People living in specific settings had fewer natural supports, while those living with their family relied heavily on it. Participants also lacked supports considered necessary. It is worth stressing that persons with IDD have also provided support to others.

**Conclusions:** Although people with IDD have generally received the assistance they need during the lockdown, it must be ensured that appropriate supports are provided regardless of the context in which they live.

## What this paper adds?

This paper is the first to analyze the consequences of COVID-19 for individuals with IDD from their own perspective. The study identifies that the supports received by people with IDD during lockdown were conditioned by the person's living context. Those living in specific settings had fewer natural supports, and those living with their family relied heavily on the family to address their needs because of service closure. To find a balance between ensuring health security conditions for people with IDD and continuing to work with them on their life project, it must be ensured that there is further development of the natural supports for those living in specific

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settings, and that the provision of supports does not depend entirely on the existence of specific services, so that supports can reach people with IDD residing in their home.

## 1. Introduction

The world we live in has been drastically transformed by the novel coronavirus—severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)—and the infection it causes, COVID-19. Three months after the reporting of the first cases of patients affected by an unknown pneumonia in Wuhan (Hubei province, China), the World Health Organization declared SARS-CoV-2 a pandemic, on March 11, 2020, when the number of people infected was 118,000 in 114 countries of whom, 4291 had died (World Health Organization., 2020).

Spain is one of the countries most affected by the pandemic, with more than 500,000 people infected, more than 29,400 casualties, a case-fatality rate of 5.9 %, and a mortality rate of 62.99 deaths/100,000 inhabitants (John Hopkins University, 2020). To counter COVID-19, the Spanish Government pronounced a State of Health Emergency on March 14, 2020 (Royal Decree 463, 2020), which extended until June 21, and entailed lockdown of the population, quarantine of affected people and their contacts, social distancing measures, reduction of nonessential economic activity, and strict hygiene measures.

Although the threat posed by COVID-19 is real for all people, the severity of the disease and the consequences of the State of Health Emergency do not affect everyone equally. One of the groups particularly vulnerable to this situation is people with intellectual and developmental disabilities (IDD). This greater vulnerability occurs in the areas of their physical and mental health, in the social sphere, and in setbacks to human rights (Courtenay & Perera, 2020).

In relation to physical health, people with IDD seem to be more likely to be infected by the virus and suffer more serious clinical outcomes of the disease (Tummers, Catal, Tobi, Tekinerdogan, & Leusink, 2020). Many people with IDD present comorbidities that can increase the severity of the COVID-19, giving rise to higher case-fatality rates (United Nations, 2020) that can double those observed in the general population, particularly among the youngest (Turk, Landes, Formica, & Goss, 2020). It must also be considered that people with IDD sometimes live in residential facilities with a high concentration of people, making it difficult to maintain social distancing measures (particularly for those who require more intensive support from professionals), which is a situation that increase the relative risk of infection (Safta-Zecheria, 2020). In Spain, it is estimated that there are more than 30,000 people with IDD who live in residential facilities or in group homes and who, therefore, are exposed to a greater risk of infection (Navas, Verdugo, Martínez, Sainz, & Aza, 2017). In addition to being more prone to contagion, people with IDD who live in residential facilities have higher case-fatality and mortality rates than people without IDD (Landes, Turk, Formica, McDonald, & Stevens, 2020).

In relation to the psychological and social consequences of the pandemic for people with IDD, the lockdown measures have meant that, for a prolonged period, people with IDD have stopped working and participating in their communities, centers and services, and have had their routines interrupted (Hughes & Anderson, 2020). In addition, for many people with IDD, it has been difficult to understand the situation surrounding COVID-19 and self-regulate their behavior, particularly for those with extensive support needs. All these factors create a risk of the appearance of challenging behaviors that negatively affect the emotional wellbeing and quality of life of people with IDD (Courtenay & Perera, 2020; Courtenay, 2020), as well as that of their family members, who in many cases have assumed exclusive responsibility for providing the supports that the person with IDD requires (Rose et al., 2020).

The conjunction of the pandemic and the measures applied to counter it also pose a threat to the rights of people with IDD (United Nations, 2020), particularly when considering the lack of planning and guidelines of the authorities in relation to social services during the pandemic (European Association of Service Providers for Persons with Disabilities, 2020). Thus, the right to health can be violated by several important factors in the context of COVID-19: lack of knowledge of healthcare professionals on how to address the needs of people with IDD during the pandemic; shortage of protective resources; insufficient accessible information on the pandemic and the measures implemented in response; decisions based on a scarcity of resources that exclude people with IDD from receiving adequate treatment due to their disability or comorbidities (European Association of Service Providers for Persons with Disabilities, 2020; Payne, 2020). In addition, the adoption of online education has not considered factors that threaten the right to education of people with IDD. Such factors are different family situations (e.g., extra cost of supports or greater family precariousness); less training of people with IDD in new technologies; inaccessible learning environments; and lack of teacher training in the needs of students with IDD (EASPD, 2020; Esentürk, 2020). Measures such as that of a lockdown can increase family overload, and this can lead to negative consequences for people with IDD, particularly considering that for many people, it has not been possible to access professional home support (Courtenay, 2020). Finally, although countries such as Spain have taken measures to facilitate the lockdown of people with IDD (e.g., regulation allowing therapeutic outings and developing technology-based supports), many services considered essential for this group have remained inaccessible, thus leading to setbacks in progress that had been previously achieved and reducing the participation of people with IDD in the community (Plena inclusión, 2020a).

In the months that have followed the spread of the pandemic, research on SARS-CoV-2 and COVID-19 has become prolific, particularly in the field of biomedicine, with particular emphasis being placed on the development of a vaccine to prevent contagion (e.g., Folegatti et al., 2020) and on finding effective treatments to combat COVID-19 (e.g., Beigel et al., 2020). There has also been an increase in publications on COVID-19 in the field of IDD; however, individuals with IDD have not yet been given a voice in such research (European Association of Service Providers for Persons with Disabilities, 2020). When writing the present study, the authors searched for articles published in English and Spanish between March and July 2020 in the main international databases (i.e., EBSCO, Scopus or WoS) using terms such as “covid-19” or “coronavirus” or “2019-Ncov” AND “intellectual disability” or “mental retardation” or “learning disability” or “developmental disability”. In the 52 documents retained after removing duplicates, there was a great variety of topics. For example, research analyzing the vulnerability of people with IDD to COVID-19 (e.g., Courtenay, 2020; Courtenay

& Perera, 2020); guidelines created to improve care and supports for this group during the pandemic (e.g., Luckasson & Schalock, 2020); case studies (e.g., De Cauwer & Spaepen, 2020); epidemiological studies (Landes et al., 2020; Turk et al., 2020); and studies analyzing the perception of parents of children with IDD about how the pandemic has affected the lives of their children (e.g., Esentürk, 2020). However, no publications were found that address how this social and health emergency has affected people with IDD from their own perspective.

Given the vulnerability of people with IDD, the severe impact of COVID-19 in Spain and the restrictive measures applied, and the lack of research that analyzes the impact of the pandemic on the lives of people with IDD from their own perspective, the objective of this work is to report the findings of a survey applied at the national level in Spain to assess the impact that COVID-19 and the lockdown have had on people with IDD.

## 2. Methods

### 2.1. Participants

A total of 582 people with IDD ( $M = 35.6$  years;  $SD = 14.1$ ) from all Spanish regions answered an online survey. Almost two-thirds of the participants answered it directly, either independently ( $n = 238$ , 40.9 %) or with the support of another person ( $n = 135$ , 23.2 %). In the remaining cases, a family member or professional administered the survey to the person with IDD as an interview ( $n = 209$ , 35.9 %). Table 1 presents the distribution of the participants according to different sociodemographic variables.

### 2.2. Instrument

To analyze the impact that COVID-19 and the response measures applied by the Spanish Government have had on the lives of people with IDD during the lockdown, the online survey was developed using the following sources: (a) literature review on coronavirus and its impact on the health and living conditions of people with disabilities; (b) reports and guidelines issued by international organizations on the potential risks posed by the coronavirus pandemic in the social, psychological, family, and health spheres of people with IDD; and (c) institutional repositories and websites that collect information on COVID-19 and people with IDD. In addition, based on the quality of life model proposed by Schalock and Verdugo (2002), a series of questions were included to analyze the impact of this current crisis in relation to the eight domains that constitute a life of quality (Schalock, 2018).

From the analysis of these sources, a set of preliminary questions was shared with a team of seven experts in the area of IDD. The team was composed of professionals from the fields of medicine, law, psychology, and sociology. Through this process, the questions to be included were discussed through two videoconferences, as was the way they should be worded and organized into sections. No modifications were made to the questions included, since all the experts agreed in their importance, and no new questions were considered necessary. Once the team of experts agreed the survey was appropriate and useful for capturing the desired data, it was sent to a group of people with IDD and their relatives, who also discussed the relevance of the questions and made modifications related to the need to register the possibility that the person was 'studying and working', and the appropriateness of presenting the person only those questions that needed to be answered based on his/her previous responses. The survey used in this study emerged from this last step, and was validated as easy-to-read by an expert in cognitive accessibility and a person with IDD (examples of easy-to-read

**Table 1**  
Participants' sociodemographic characteristics.

Variable	N	%
<i>Gender</i>		
Male	279	47.9
Female	303	52.1
Total	582	100
<i>Age group</i>		
Up to 21 years old	84	14.4
Between 22 and 44 years old	344	59.1
45 years old or older	154	26.5
Total	582	100
<i>Housing type</i>		
Own house	63	10.8
Family house	401	68.9
Group home	55	9.4
Residential facility	51	8.8
Another place	12	2.1
Total	582	100
<i>Occupation</i>		
Study	135	23.2
Work	195	33.5
Study and work	42	7.2
Neither work nor study	210	36.1
Total	582	100

questions are presented in Table 2).

The survey includes 41 closed questions across the following five sections: (a) instructions, which emphasizes that the survey refers to the lockdown in Spain and includes the informed consent form (one question); (b) sociodemographic data (nine questions); (c) impact of the pandemic on the person (14 questions); (d) impact of the pandemic on the person's living conditions (eight questions); and (e) perception of quality of life (nine questions). In addition, seven open questions were included to gain understanding about the former and to capture the individual perceptions (i.e., voice) of people with IDD. These open questions are the object of analysis in this research and are presented in Table 2.

### 2.3. Procedure

The research team made initial contact with Plena inclusión, which is the main service provider in Spain for individuals with IDD and offers support to 140,000 individuals through nearly 900 organizations (Galván, 2020). In the initial correspondence, the survey was emailed by Plena inclusión to each organization requesting their participation in the study by disseminating the survey among individuals with IDD. To reach people who do not attend services or are supported by other service providers, the online survey was also disseminated via the Plena inclusión website and social media using easy-to-read instructions. Data collection occurred between June 1, 2020 and June 30, 2020.

The survey was hosted on a university server to maximize data privacy and security. Internet protocol addresses were collected for

**Table 2**  
Coding scheme.

Question	Categories	Kappa
How did you get information about coronavirus?	Media (press and TV)	.972
	Internet and social media	.972
	Family	.992
	Friends	.948
	Disability organizations or its professionals	.946
	School or workplace	.872
	Healthcare services or healthcare professionals	.901
	Other sources	.834
What have you missed during lockdown?	Recreational activities (outdoors or without restrictions)	.947
	Contact with family and friends	.969
	Academic or training activities	.912
	Work or occupational activities	.875
	Disability services or supports	.939
	Regular routines	.839
Who has helped you better manage the lockdown situation?	Family	.995
	Disability organizations or its professionals	.978
	Other natural supports such as friends, house mates, workmates, partners	.997
	Teachers	.940
	Other people (e.g. neighbors, acquaintances)	.677
Have you helped others better manage the lockdown situation?	Family	1.00
	Friends	1.00
	House mates	.965
	Others (e.g., couples, neighbors, acquaintances)	.888
How have you helped others better manage the lockdown situation?	Emotional support	.827
	Recreational support (planning activities, spending time with others)	.864
	Instrumental support	.980
	Information and advice	.927
	Others forms of support (e.g. following rules or behaving)	.722
What things have helped you feel good during the lockdown situation?	Company and support from family members or house mates	.857
	Contact with family and friends through technology	.909
	Professional supports from disability organizations	.947
	Recreational activities at home or online	.903
	Outdoors recreational activities, with restrictions	.904
	Online training, work or volunteer activities	.817
	Others	.680
Have you missed anything to help you feel better during these weeks?	Disability services or supports	.948
	More frequent support or contact from family members	.832
	More information/advice about the current situation	.891
	Financial support	.884
	Support from society at large (empathy for people with disabilities)	.853

the sole purpose of eliminating duplicate responses. This procedure was approved by an external ethics committee of Plena inclusión given that Plena inclusión was providing the contact information of the service providers. In accordance with the principles of the Declaration of Helsinki, informed consent was included in the survey and was accompanied by an information sheet with the aims, methods, sources of funding, and other relevant aspects of the research study, including contact information to address specific questions or obtain additional information written in easy-to-read format.

## 2.4. Data analyses

Participants' responses to the open questions were approximately 20 words in length. Content analysis was performed to identify themes across participants' responses by establishing categories to organize the information gathered throughout the research, and served as a guide for understanding and interpreting the information that was collected.

After having read participants' responses several times, content analysis (i.e., coding) involved organizing raw data into categories (Baralt, 2011). Categories were defined as externally heterogeneous to avoid redundancy or interchangeability. All categories were created inductively, without trying to fit them into a pre-existing coding framework (Pope, Ziebland, & Mays, 2000). The categories were created by the first author and reviewed by the research team. Minor doubts in categorization were resolved by discussion among the research team until consensus was reached. The final coding scheme was then used by the first author to code the entire dataset (Table 2). To minimize risk of bias or potential errors, two researchers (first and second author) coded participants' responses and calculated interrater agreement using Cohen's Kappa coefficient. Agreement was interpreted according to the following criteria (Viera & Garrett, 2005): slight agreement (0.00–0.20), fair agreement (0.21–0.40), moderate agreement (0.41–0.60), substantial agreement (0.61–0.80), and almost perfect or perfect agreement (0.81–1.00). Almost perfect agreement was reached for 92.5 % of the categories (values ranging from .817 to 1.00), being substantial the agreement among researchers for the remaining three categories (values ranging from .677 to .722).

To search for differences between respondents, qualitative data were transformed into quantitative data following a present or absent approach based on whether the theme appeared in the response (1) or not (0) (Sandelowski, Voils, & Knafl, 2009). When using open questions in a survey, not all respondents write answers to the questions (O'Cathain & Thomas, 2004). To include this phenomenon in our data analysis, the number of respondents addressing each category is also reported.

Chi-square tests were employed to estimate the statistical significance of the relationship between the likelihood of reporting a specific category and certain demographic characteristics of individuals with IDD (i.e., residential context or age group). Data were analyzed using IBM SPSS v. 25.

## 3. Results

### 3.1. Sources of information

A total of 89.5 % ( $n = 521$ ) of participants reported having received information about the coronavirus, with 81.0 % of these cases stating the information was easy to understand. In general, the main source of information was the disability organizations or their professionals (46.6 %), followed by the media (45.3 %) and families (35.5 %). Of the participants who studied and/or worked ( $n = 331$ ), only 12.7 % stated that they had received information from their school or workplace. In addition, only 3.5 % of participants reported that they received coronavirus information from health centers.

Almost half of the sample ( $n = 237$ ) reported having received coronavirus information from different sources. The sources of information varied, depending on the person's living context, with disability organizations or their professionals being the principal source of information (and the only one in the 61.0 % of the cases) for participants living in specific settings (Table 3).

### 3.2. Effects of Lockdown

Most of the participants (91.1 %) specified what they missed during the lockdown. The most noted consequence of lockdown for people with IDD was reported to be its impact on social relationships. Contact with family and friends was undoubtedly the most prominent factor of change reported by participants (74.5 %), regardless of their age or living context. For example, i213 stated, "I

**Table 3**

Sources of information depending on the living context.

Living context	Services depending on organizations ( $n = 101$ )	Family/own home ( $n = 409$ )	$\chi^2$	$p$
Disability organizations or its professionals	84 (83.2 %)	152 (37.2 %)	68.9	<.001
Media (press and TV)	37 (36.6 %)	195 (47.7 %)	8.17	<.05
Family	11 (10.9 %)	169 (41.3 %)	32.8	<.001
Internet and social media	4 (4.0 %)	49 (12.0 %)	–	–
Friends	3 (3.0 %)	16 (3.9 %)	–	–
School/workplace	2 (2.0 %)	43 (10.5 %)	–	–
Healthcare services or healthcare professionals	1 (1.0 %)	17 (4.2 %)	–	–

\*Those who are under 21 years old are excluded because only five of them lived in settings depending on organizations.

\*Chi-square tests have not been conducted for those cases in which observed frequencies were under five.



missed my sister, I had to separate from her. I missed my friend because I was not going to face-to-face class” and i256 stated, “I miss my family, my boyfriend, my colleagues and friends. I miss going downtown, to the gym, for a walk.”

Other notable activities that were missed included recreational or leisure activities (45.1 %) or specific professional services and supports (20.0 %). For example, i246 reported missing “[a]ttending the day center and not being able to see the rest of my family and friends” and i237 reported missing “[b]eing with friends, going out for a drink, eating out and sharing with friends, going to my occupational center, and in a nutshell, many things.”

To a lesser extent, work (9.1 %) or academic (7.4 %) activities were reported as being missed. However, it should be noted that 36.7 % of the participants aged 3–21 years who were studying ( $n = 68$ ) mentioned missing their daily activity, a percentage that decreased to 20.7 % among those who were working ( $n = 231$ ). For example, participant i229 stated that he wanted to go back to “school, go to eat at my grandparents’, swim, and enjoy leisure on Saturdays.” This age group (i.e., 3–21 years) reported missing recreational or leisure activities significantly more than did the two remaining age groups (57.1 %), who mentioned missing these activities in 40–45 % of cases ( $\chi^2(2, N = 530) = 6.9, p < .05$ ). For example, participant i017 stated missing “[b]eing able to go out with my friends, being with my grandmother one day, going to the village and going shopping, and I have also missed swimming lessons.”

However, among the oldest age group, statistically significant differences were also observed depending on the living context in relation to the usual availability of recreational or leisure activities. Missing recreational or leisure activities was notably reported more by those older than 44 years of age living in specific settings compared with their same age peers who lived with their family or in their own home (Table 4). A greater number of references to missing contact with family or friends was also observed in this age group than in the other two age groups.

### 3.3. Support networks

In total, 478 participants (82.1 %) stated they had received support during the lockdown. Of these, 29.5 % reported having received support from more than one person. No differences were observed for age, gender, or living context in relation to having received support.

The main supports indicated were family (72.8 %) and organizations or their professionals (37.0 %). For example, participant i480 stated, “[m]y mother, my aunt, and my grandparents call me at the residence to know how I feel and to encourage me. I’ve missed them so much. During the coronavirus I had to be separated from my other companions for two weeks and we were in other bedrooms in the upper part of the residence: the truth is, this was a very difficult experience” and participant i245 reported receiving support from “[m]y family and a psychologist from my association who comes to my house. Since the coronavirus, we make weekly video calls.”

Friends, roommates or workmates, and partners were less reported as a source of support (15.9 %). It should be noted that only nine participants (13.2 %) in the age group 3–21 years who were studying mentioned having received support from teachers or the school. Thus, participants younger than 21 years of age seem to have been supported mainly by their families (89.0 %), with mention of receiving professional or specific support significantly lower than in the two other age groups ( $\chi^2(2, N = 478) = 28.8, p < .001$ ).

Among adults (Table 5), the living context also seems to be significantly associated with specific support sources, regardless of age or gender. Thus, while those living in specific settings seem to have had fewer natural supports, those living with their family have largely depended on the supports provided by the family.

It is worth highlighting that people with IDD have not only received support during coronavirus, but they have also provided support to other people. That is, 300 participants (51.5 %) reported having provided some type of support to other people during the lockdown, without differences observed based on age or gender. In addition, 12.7 % of these participants reported having supported more than one person. Generally, the participants reported having supported family members (55.0 %), roommates (25.3 %), and friends (22.3 %), with fewer mentions of having supported their partner or other people such as neighbors or acquaintances (11.4 %). The most frequent type of support consisted of revitalizing day to day routines through playful activities (41.8 %), followed by

**Table 4**  
Aspects missed by participants regarding age group and living context.

Age	22–44				+45			
	Living context							
	Services depending on organizations ( $n = 38$ )	Family/own home ( $n = 269$ )	$\chi^2$	$p$	Services depending on organizations ( $n = 55$ )	Family/own home ( $n = 82$ )	$\chi^2$	$p$
Contact with family and friends	26 (68.4 %)	201 (74.7 %)	.68	.408	47 (85.5 %)	56 (68.3 %)	5.19	<.05
Recreational activities	20 (52.6 %)	117 (43.5 %)	1.1	.289	31 (56.4 %)	21 (25.6 %)	13.22	<.001
Disability services or supports	4 (10.5 %)	53 (19.7 %)	–	–	12 (21.8 %)	20 (20.4 %)	.12	.727
Work or occupational activities	5 (13.2 %)	34 (12.5 %)	.01	.928	1 (1.8 %)	5 (6.1 %)	–	–
Academic or training activities	2 (5.3 %)	12 (4.5 %)	–	–	0	2 (2.4 %)	–	–
Routines in general	1 (2.6 %)	11 (4.1 %)	–	–	0	3 (3.7 %)	–	–

\*Those who are under 21 years old are excluded because only five of them lived in settings depending on organizations.

\*Chi-square tests have not been conducted for those cases in which observed frequencies were under five.

**Table 5**  
Support sources considering age group and living context.

Living context	22–44				+45			
	Services depending on organizations (n = 34)	Family/own home (n = 237)	$\chi^2$	p	Services depending on organizations (n = 54)	Family/own home (n = 73)	$\chi^2$	p
Disability organizations or its professionals	26 (76.5 %)	61 (25.7 %)	35.11	<.001	45 (83.3 %)	24 (32.9 %)	31.84	<.001
Family	8 (23.5 %)	198 (83.5 %)	58.7	<.001	13 (24.1 %)	61 (83.6 %)	45.17	<.001
Other natural supports such as friends, house mates, workmates, partner	9 (26.5 %)	36 (15.2 %)	2.7	.098	9 (16.7 %)	11 (15.1 %)	.06	.807
Teachers	0	4 (1.7 %)	–	–	–	–	–	–

\*Those who are under 21 years old are excluded because only five of them lived in settings depending on organizations.

\*Chi-square tests have not been conducted for those cases in which observed frequencies were under five.

emotional (31.8 %), and instrumental support (20.7 %). To a lesser extent, the participants provided information and guidance on the health emergency (13.0 %) or supported via other ways (7.7 %). In addition, 14.7 % claimed to have provided more than one type of support.

Although no statistically significant differences were observed in relation to the type of support provided according to age and gender, the youngest age group (3–21 years) reported having mainly helped their family (71.4 %) through recreational activities (40.0 %) or providing emotional (28.6 %) or instrumental supports (28.6 %). For example, participant i47 stated having helped at home by “[p]laying at home and making laughing videos” and participant i150 reported having helped her mother by “[d]oing the household chores and with a smile. Thanking my family for the meals they make.” For the adult age groups, it should be noted that those living in services that depend on organizations claimed to have provided help to others to a greater extent than those living in the family home ( $\chi^2$  (1, N = 489) = 13.3,  $p$  < .001; 70.0 % vs. 49.0 %). In both types of living context, the type of support provided seemed to be limited to the people they lived with (i.e., family or roommates/housemates). For example, participant i268 reported having helped “[m]y parents, doing the shopping for them” and “friends by [conducting] videoconferences” and participant i350 reported having helped “[m]y mother, taking care of her because she is sick, and I have to shower and help her” and “my father so that he would not be nervous and not shout. I have been in charge of doing the shopping, cleaning the house, cooking, accompanying my parents to the doctors, and answering the phone.”

Adults with IDD living in specific settings reported having provided emotional support (44.3 %) more than those living with their family or in their own home (26.8 %; [ $\chi^2$  1, N = 260] = 7.2,  $p$  < .01), with no differences in relation to the living context observed in other types of support. For example, participant i159 reported having helped her roommates by “[e]ncouraging them, staying with them when they are sad” and participant i188 reported having helped people in her residence by “[e]ncouraging them, making them laugh, and playing games and watching movies.”

### 3.4. Specific supports during the lockdown

Most participants (n = 578) answered the question about what specific supports they had to feel good during the lockdown. Only 15 (2.6 %) said that they did not need support and 31 (5.4 %) stated that they had not had any help. For example, participant i38 stated, “[n]one. On the contrary, my rights have been violated.” The other participants (n = 532) referred to various types of support that had made them feel good during lockdown, highlighting the company and support of those they lived with (75.0 %) and the performance of online or at-home leisure activities (62.8 %). For example, a young participant who lived with her family (i236) stated, “I have been able to be with my parents and sister, we have listened to music, exercised, danced, and played together. My mother has helped me to do my homework, she has taught me recipes and I have danced a lot with my father.” A participant in the age group of older than 45 years of age living in a residential facility noted that it helped to “[h]ave daily meetings with my roommates and my support staff to talk about how we feel and what goals we have to achieve to feel good, for example, doing a sport that I choose everyday.”

Contact with others through technology (30.6 %) and specific professional supports (28.8 %) were also reported as important aids that have been available during the lockdown. For example, participant i304 highlighted as a support “[talking] to the psychologist and caregivers about how I feel and to encourage me. Calling my loved ones.” To a lesser extent, the participants mentioned the following as examples of supports during lockdown: outdoor activities (10.5 %); the possibility to continue working, receiving training or doing occupational or volunteering activities (7.3 %); and other types of supports such as having the opportunity to help at home or receive information about the situation (9.2 %).

As observed when analyzing the support networks of people with IDD had during the lockdown, living context seemed to condition the help they have received to feel better. For example, specific professional supports were reported as a major source of support for participants living in group homes or residences (Table 6).

Participants also reported lacking support considered necessary during the lockdown. Specifically, 116 participants (19.9 %) reported needing supports that they did not have. Most indicated not having had the specific services or professional supports they needed (50.9 %); not having more frequent contact or support from family members or close social circle (32.8 %); and not having information and advice on the situation (9.5 %). To a lesser extent, participants reported not having necessary financial support (4.3 %)



**Table 6**

Supports received by persons with IDD to feel better during the lockdown regarding the living context and age.

Living context	22–44				+45			
	Services depending on organizations (n = 41)	Family/own home (n = 268)	$\chi^2$	p	Services depending on organizations (n = 57)	Family/own home (n = 82)	$\chi^2$	p
Company and support from family members or house mates	29 (70.7 %)	205 (76.5 %)	.64	.423	32 (56.1 %)	66 (80.5 %)	9.58	<.01
Recreational activities at home or online	28 (68.3 %)	172 (64.2 %)	.26	.608	32 (56.1 %)	51 (62.2 %)	.51	.474
Contact with family and friends through technology	16 (39.0 %)	81 (30.2 %)	1.27	.258	12 (21.1 %)	28 (34.1 %)	2.08	.094
Professional supports from disability organizations	17 (41.5 %)	62 (23.1 %)	6.27	<.05	31 (54.4 %)	26 (31.7 %)	7.14	<.01
Outdoor recreational activities, with restrictions	10 (24.4 %)	26 (9.7 %)	7.45	<.01	3 (5.3 %)	7 (8.5 %)	–	–
Online training or work activities	2 (4.8 %)	22 (8.2 %)	–	–	4 (7.0 %)	8 (9.8 %)	–	–
Others	1 (2.4 %)	28 (10.4 %)	–	–	7 (12.3 %)	8 (9.8 %)	.22	.637

\*Those who are under 21 years old are excluded because only five of them lived in settings depending on organizations.

\*Chi-square tests have not been conducted for those cases in which observed frequencies were under five.

or greater understanding by society in general of the situation of people with IDD during the State of Health Emergency (2.6 %).

The younger participants seem to have particularly lacked the professional services and supports that were necessary. For example, participant i050 stated, “I have missed not being able to continue with some activities to improve and advance (speech therapy, swimming...)” In fact, 76.7 % of the younger participants who mention having been deprived of some necessary supports, highlighted lacking professional services and supports that were necessary, compared with 42.0–43.0 % of those aged between 22 and 44 and older than 45 years ( $\chi^2$  (2, N = 116) = 10.81,  $p$  < .01).

When identifying the different supports that were lacking during lockdown, the participants living in specific settings reported having missed more frequent contact with family members or close social circle (52.6 %) to a greater extent than did the participants living with their family or in their own home (29.0 %) ( $\chi^2$  [1, N = 116] = 3.97,  $p$  < .05).

Those living in the family home indicated a greater need (54.8 %) for professional services or supports that have ceased to be received or have been received to a lesser extent because of the lockdown compared with participants living in specific settings (26.3 %), resulting in a statistically significant difference ( $\chi^2$  (1, N = 116) = 5.13,  $p$  < .05). When explaining this, participants alluded mainly to the interruption of occupational (“I have missed having online classes with the occupational center”; i023) and educational services (“When doing my homework, I have not had the person who sends them in front of me to tell me if I’m wrong”; i028); and the interruption of other types of supports (“I have missed help with moving around in places where I could go out, due to my reduced mobility”; i092).

#### 4. Discussion

This study analyzed the impact that COVID-19 and the response measures implemented by the Spanish Government have had on the lives of people with IDD from their own perspective. Detailed knowledge of the perspectives of people with IDD is essential for understanding the consequences of lockdown for this group. This study has examined the qualitative results obtained from the analysis of seven open questions included in an online survey.

People with IDD reported having received information about the coronavirus mainly from disability organizations and their professionals, highlighting that such information was generally easy to understand. Therefore, it is worth stressing the active and important role played by such organizations during the State of Health Emergency. For example, throughout the lockdown in Spain, the organization *Plena inclusión* has organized more than 20 informative seminars on the State of Health Emergency, has published 12 information guidelines, and has adapted more than 80 documents on the coronavirus to an easy-to-read format (e.g., *Plena inclusión*, 2020a).

Other sources of information for people with IDD have been the media and their own families. However, only 3.5 % participants reported that healthcare centers provided them with information on the coronavirus and the government’s response measures. Previous research has pointed out that many barriers exist in health information exchange between individuals with IDD and healthcare professionals (e.g., Mastebroek, Naaldenberg, Lagro-Janssen, & de Valk, 2014). This might explain why individuals with IDD have not received information from their healthcare centres, although we have to take into account that information on health preventive practices regarding COVID-19 was constantly transmitted by the media, being this the same information that healthcare centres could offer.

Contact with family and friends was an important support factor that was missed during the lockdown, regardless of participants’

age, gender, or living context. Recent studies (e.g., Embregts et al., 2020) have also found that individuals with IDD missed being close to their loved ones and, although social interaction has changed for all, it is necessary to consider and reduce possible difficulties that people with IDD may encounter in accessing technology, so that they do not experience diminished social interactions. Enhancing online contact with others might also reduce the anxiety caused by a situation of uncertainty that may be difficult to understand for some of them (Zaagsma, Volkers, Swart, Schippers, & Van Hove, 2020).

The other support factor highlighted as being lacking by people with IDD was recreational or leisure activities, particularly in the case of young people. Families have experienced difficulties helping their children adapt to new routines during the pandemic (Cahapay, 2020; Esentürk, 2020) and this may have resulted in academic or health preventive practices being initially prioritized over leisure activities. However, individuals older than 44 years of age who live in specific settings also missed these activities, perhaps because their outings have been more restricted in these living contexts since they have been limited to making essential purchases, and these were often made by professionals due to mobility restrictions. As some researchers note (Embregts et al., 2020; Hughes & Anderson, 2020), the lockdown measures have caused people with IDD to have their routines interrupted by ceasing to attend, work, and participate in their healthcare centers and communities, and different services have prioritized addressing and responding to the basic needs of people with IDD rather than leisure activities.

In relation to the supports received during the lockdown, the responses of people with IDD indicate that they have received the necessary supports, regardless of their age and gender. However, the nature of this support is conditioned by the person's living context. That is, while those living in specific settings seem to have had fewer natural supports, those living with their relatives have relied heavily on the supports provided by them and missed professionals supports. This indicates the need to rethink two fundamental factors: (a) the extent to which focus is placed on the development and maintenance of natural support networks when the person lives in a specific setting; and (b) the degree to which service providers support families when the person lives in the family home. Regarding the development of natural supports for those living in specific settings, this situation should lead us to promote forms of provision of supports that prioritize life in the community and in natural environments such as personal assistance, which remain underdeveloped in our country (Navas et al., 2017). This would prevent the person from failing to receive the necessary supports in a facility closure scenario. In relation to collaboration between families and disability services when the person lives at her or his family home, family-centered practices are clearly more needed, as they constitute a key factor for parental autonomy and wellbeing (Mas et al., 2019; Vanderkerken, Heyvaert, Onghena, & Maes, 2020).

The support provided by family is particularly evident in the youngest age group (3–21 years); this age group reported not having received the necessary support from their school and other services that have been suspended during the lockdown, leading to possible family overload as found in recent studies (Rose et al., 2020; Willner et al., 2020). As pointed out by the main service provider for individuals with IDD in our country, families supporting their children with special needs during lockdown are more likely to be single-parent families and suffer most from inequality (Plena inclusión, 2020b), this situation making difficult for them to provide academic support since they also might lack specific knowledge on which methodologies or activities to use (Esentürk, 2020). Despite the efforts made by teachers, the State of Health Emergency and the closure of schools have revealed the difficulties schools have encountered in responding to the needs of students with IDD. This may be due, among other aspects that require further study, to the poor implementation of universal design for learning in our classrooms (Simón & Echeita, 2016), one of the primary ways to promote accessible learning environments for all students.

Families have had to make extensive efforts to make their family and work life compatible, and this is increased in households with a child with IDD, particularly in the case of children with extensive support needs (Esentürk, 2020). The interruption of routines and ongoing supervision (since support from schools was scarce) have burdened families, highlighting the need to develop networks of collaboration and understanding between teachers and families on how to support students with IDD, a topic that constantly emerges in the literature about this matter (e.g., Esentürk, 2020; Verdugo, Amor, Fernández, Navas, & Calvo, 2018). As schools reopen, the experience gained during lockdown has led to the development of strategies that prevent the shortcomings of the educational system when supporting students with IDD in both face-to-face and online education. Chief among the strategies developed with this purpose are: (a) developing clear contingency plans to ensure security for all students, including the reduction of ratios, which also contribute to maximize supports for learning and participation of students with IDD (Plena inclusión, 2020c); (b) providing emotional support to manage the potential psychological consequences of the lockdown (Maryland State Department of Education, 2020); (c) adopting new methodological approaches to education, like personalized educational plans which ensure technological aids that respond to students' needs and learning goals (Vega, Navarro, Pérez, & Guerrero, 2020), or the implementation of universal design for learning and multilevel curriculum (Plena inclusión, 2020c); and (d) the development of transition plans, agreed with families, from face-to-face to online education that ensure that no child is left behind (Cheshire, 2020; Plena inclusión, 2020c; Vega et al., 2020).

Supports for those individuals who were not studying but working were also necessary. Although lacking supports to perform their work was not a topic highlighted by participants who were working, a study being conducted by the authors indicates that the majority of workers with IDD have not been able to continue working during the pandemic as they used to, being their activities interrupted in most cases. There is therefore an urgent need for research focusing on how the pandemic has affected the employment of people with IDD.

A fundamental finding of this study is that people with IDD have not only received support during the lockdown, but have also provided such support, mainly to their family members or to the people with whom they live. This highlights the active role that individuals with IDD have played during the lockdown in their closest environment, and should encourage professionals and family members to promote the active role that people with IDD can play, as they are often only seen as recipients of services.

Finally, the pandemic and its consequences have created a situation of uncertainty about the future, anxiety, and stress for professionals, families, and people with IDD, all of whom have seen their lives altered by having to change their daily routines and face a

completely unknown situation that has highlighted the difficulties of the system at all levels: education, employment, health, and social services. Such difficulties have led to the violation of many of the rights of people with IDD that are stated in the United Nation's Convention, such as the right to information, health, education, accessibility, or habilitation and rehabilitation, making it necessary to adopt measures that in similar future scenarios, will ensure that a group that is particularly vulnerable will not experience further exclusion.

This study has some limitations that must be acknowledged. First, the study did not explore possible differences in the impact of COVID-19 among people with IDD according to variables such as the intensity of support needs. Information about the severity of ID or support needs was not asked, since these might be questions difficult to respond for some of the participants. Readers should take into account that this study may represent the perceptions of people with IDD and lower support needs. In addition, given the need to administer the survey online because of the lockdown, people with IDD that have difficulties accessing technology or have communication problems may have been unable to access the study, and have therefore been excluded.

Individuals with extensive or generalized support needs might be more affected by the lockdown because they experience comorbidities that place them at a higher risk of infection (Safta-Zecheria, 2020) and rely heavily on services that have been suspended or reduced. To address this limitation, the research team is conducting a study on the impact of COVID-19 on families of people with IDD in which the variable "support needs" is included to analyze the impact of the pandemic on those with more severe disabilities.

Second, given that completing the survey was voluntary, there is the possibility that it might have been answered only by people with IDD who are more sensitive or concerned about the situation surrounding COVID-19.

Third, authors were not able to adhere to the principles of data saturation (Carlsen & Glenton, 2011). Because these analyses were part of a larger study focused on the impact of COVID-19 on individuals with IDD, obtaining a large sample was crucial. It was therefore not possible to study the point at which no more sample is needed in order to cover all aspects of interest within participants' responses as suggested by methodological literature on qualitative data analyses (e.g., Fugard & Potts, 2015).

Despite these limitations, this study is the first at the time of writing that captures the perspectives of people with IDD on how the COVID-19 pandemic has affected their living conditions, and can serve as a starting point for improving the provision of support if a similar situation arises in the future.

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## CRediT authorship contribution statement

**Patricia Navas:** Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing - original draft, Writing - review & editing, Visualization, Project administration. **Antonio M. Amor:** Conceptualization, Methodology, Investigation, Data curation, Writing - original draft, Writing - review & editing, Visualization. **Manuela Crespo:** Conceptualization, Investigation, Writing - original draft, Writing - review & editing, Visualization. **Zofia Wolowiec:** Conceptualization, Data curation, Writing - original draft, Writing - review & editing, Visualization. **Miguel Á. Verdugo:** Conceptualization, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration.

## Declaration of Competing Interest

The authors report no declarations of interest.

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